

## **Overview of Developmental Disabilities Services Vision and Challenges**

### **Backdrop for Future Vision**

- Since the mid 1980s, the landscape for the role of people with developmental disabilities in our communities has changed significantly
- This has been shaped by a combination of events, including strong grass roots advocacy for education and supports that are tailored to the individual's participation in community and family, changes in public policy and the public's understanding of this disability, more flexibility in using funds, and landmark legal decisions regarding the civil and legal rights of individuals
- We are currently in a transitional phase. Expectations of families and participants that are part of the younger generation really no longer have institutional services as part of the landscape. Four bed foster homes are not part of the landscape. And day programs that are not offering real work choices are not part of the landscape.
- Our approaches to public policy making and to the management of services are challenged to keep up with this very fundamental shift. Our thinking and our service system infrastructure....how we allocate money, how we deal with the feds, what models of services we financially support and incent.....must transition if we desire to meet the needs and expectations of this next generation of people.

### **Vision**

The vision for people with developmental disabilities is a simple one. We desire to help support people in accessing those things that most of us want and that society values. Whether we like to admit it or not, society does "value" people based upon certain things....your family ties, having a home of your own, your job or profession, your contributions to community.

It is our belief that people with developmental disabilities simply want these same things so that they are treated as equals in our society. Without these things, people are labeled as somewhat "less than" everyone else around them.

It is true that people with disabilities may need some support from us to achieve this vision. But, it is our belief that public funding is well used when we arrange it so that people are able to contribute back to their families and their

communities. That is the underpinning of the public policy that we endorse for the future.

### How Does This Translate to Public Programs?

Our public programs have to change if we really and honestly believe in this vision. This presents a lot of challenges, but it can be done. Think of how far we've come in the last 25 years. The next leap probably is not as big as that one.

So, how should our public programs change?

- We need to pay more attention to the housing choices available to people. We've structured services to be somewhat flexible, but we have failed to have a way for people to get to a home in which they have ownership or control. So, it leaves us reliant upon providers to set up models that are really the most expensive approach we can take for the future.
- We need to pay more attention to job opportunities. Kids transitioning from public schools need easier pathways to getting employed. Employment equals buying power and more independence. Employment means taking personal responsibility for one's needs. And employment is something to which we, as a society, attach value to the person.
- We need to pay more attention to allowing people to direct where support dollars go in helping them achieve whatever level of independence is possible. Giving people services that don't really achieve an outcome of increased independence, or of maintaining whatever independence a person has now is not a good use of public money. Yet, we have a long way to go in determining how best to do this and how to hold people accountable for the results.

What kind of leadership is needed?

- The transition will not occur simply because DHS or ARC or ARRM want something done. The leadership that is needed will come from a cooperative relationship among legislators, executive branch, stakeholders, and people with disabilities.
- Since the fight around institutions concluded, we all have struggled with focus and common cause.
- DHS invites and welcomes others to talk with us about shaping the vision and the public policy around helping people to have homes, have jobs or meaningful activity, and to direct the supports that help them achieve or maximize independence.

## Some Challenges that are Upon Us

I want to comment about three specific challenges that come with moving toward the vision: 1) agreement about the role of government in achieving the vision; 2) getting out of old models of service into supporting people in new ways; 3) knowing when we've actually achieved the vision. (notice, I didn't mention funding)

### The role of government:

Sitting in my chair within DHS I sometimes feel as though it is expected that we are: a) responsible to meet every desire that anyone has for their life; and conversely, 2) responsible to hold the line on government supplanting the responsibility of the individual or their family. It strikes me very frequently that we have not done a good job of defining the role and the extent of the obligation of government. As a result, some people with disabilities expect a lot, and some people don't even know they could expect something.

Entitlement is something that in government we define through the words we use in state plans and waiver programs. It is defined by the dollars appropriated. Yet, people don't really know...in a clear way...what should be or must be our obligation.

From my perspective, there are three levels of discussion to have about the role of government and public programs: 1) our obligations to protect the health and welfare of people; 2) our obligations to offer services which promote independence and enhance skills; 3) our obligations to assure an acceptable and appropriate quality of life. In today's reality, these obligations remain somewhat unclear. A strength of our system is the extent to which we allow individually tailored planning. The challenge to our system is that this flexibility has created some perceptions that government is obligated to support and pay for things we've really never imagined. In the future, flexibility and the ability of people to direct how supports are provided is KEY to achieving the vision. But, we must couple this with clearer definitions about what government services will be obligated to offer and provide.

### Moving from the Old to the New/Models of Service

Minnesota's services for people with developmental disabilities is over reliant upon old models of service. Both the current residential and day program structure is outdated for those people who are now entering service. The current structure was designed and has worked well to help people leave

institutional services. But, in the future we need to develop other ways to support people. Not only is this potentially better for the people involved....if done well....but it makes us as a government entity less reliant on a very expensive approach to providing support.

Transitioning out of these models is unsettling for those who have worked hard to develop them. This is certainly true for providers of ICF/MR services and for waiver services using corporate foster care as the basis for the residence. It is also true for our hard working providers of Day Training and Habilitation who have been caught in between an old system of bundled activities for which they get paid, and the desire of people to receive support on real job sites or engaged in activities which are selected by the consumer because of their personal interest and need for fulfillment.

We are NOT proposing a sweeping change which eliminates these good service providers. But, we are saying that the models are dated and that change will come. The challenge is that we have limited ways currently of funding the transition to allow for the change in the business model (downsizing is an example). This complaint from the provider community is a legitimate one. But, it is not solely the state's responsibility for this. Providers who continue to invest new dollars in dated models cannot expect government to guarantee the viability of their business into the future. And providers must be willing to hold some of the risk for their business future.

Knowing when we've achieved (or haven't) the vision:

The landscape of service has changed from one of people being served in a defined number of facilities to a landscape of people being served in a million different ways. In the process of achieving this, we have struggled to maintain a business process that checks, monitors, and corrects problems having to do with the integrity of our services.

We know a lot about caseload numbers and dollars spent. We know somewhat less about the availability and the expertise of providers to meet the requirements of the job. And we know less that either of these about whether services actually resulted in improving people's lives. In other words, we are at a critical juncture of rethinking how we manage this sprawling system so that we are more responsive to quality problems, more efficiently managing resources, and are holding stakeholders (and ourselves) to achieving the outcomes we've promised.

In the future, as a public body, we must be able to have access to information in a timely way that tells us about our service system. Then we

must use that information to correct problems and to promote good policy and practice. We must hold ourselves accountable for both how well our public policy is performing on the whole, and how well things are going for the individual person. We should have benchmarks to compare these things against, so that we can really say we have achieved our goals.

#### Closing Remarks

Thank you for the opportunity to speak with you today. I started my career in the mid seventies moving people to community services from state institutions. It was a wildly unpopular thing to do. Communities were afraid. Families were afraid. Many of us were threatened, yelled at, and we were the targets of public displays of anger intended to invoke terror. But people fought and I am so very proud of the progress that has been made.

Now it is time to harness the passion that still remains from those days toward a very different future and set of challenges. My work away from those front lines in the bureaucracy has sometimes been frustrating because we don't all agree with each other about how to get to where we want to go. But, because of the foresight of the leaders in disability services we have the luxury of great common ground upon which to build in this State.